

# Update on Alzheimer's



## Improving the Quality of Life in Patients with Alzheimer's Disease

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### INTRODUCTION

Alzheimer's disease (AD) is a devastating illness with no cure, and because of this, improving the quality of life of patients with AD at every stage of the disease should be a primary concern of psychiatrists. In this article, I discuss several ways that

psychiatrists can improve the quality of life of patients with AD. It is emphasized throughout the article that at all stages of AD, a patient's quality of life can be determined not only by the extent of his or her cognitive decline, but by his or her social interactions with others.<sup>1–4</sup> Thus, the

psychiatrist should continue to maximize social interaction, both therapeutically and pharmacologically, as much as possible.

### SCREENING PATIENTS FOR MINIMAL COGNITIVE IMPAIRMENT AND AD

When patients present with complaints of poor memory, psychiatrists should first determine whether they have minimal cognitive impairment (MCI) or early AD. Psychiatrists may do this initially by using a brief, less sensitive screening test, such as the Mini-Cog, which includes simply a clock drawing and delayed recall. If the results of this test are normal, then a longer, more sensitive test, such as the Montreal Cognitive Assessment (MoCA) or the Mini-Mental State Examination (MSSI) should be pursued.<sup>5–7</sup> If the results of both tests are normal, the psychiatrist can (at least temporarily) reassure these patients. If the results of the tests are “positive” for MCI or AD, the psychiatrist should then refer these patients for additional testing. If a patient tests normal on both tests but is still fearful, the psychiatrist should inform the patient about online computer testing.<sup>8</sup> These online tests have significant limitations since they are not clinically administered, and the psychiatrist should explain this to the patient. These tests, however, have greater sensitivity in some areas, and if the results are negative, this may further reassure the patient.

Prior to any type of screening, the psychiatrist should inform the patient about the possible outcomes and discuss the pros and cons of knowing the results of the screening.<sup>9</sup> An important benefit to undergoing screening that can be

explained to the patient is having the option to begin medication as early as possible should the results of the screening indicate MCI or early AD. Another benefit to having the screening, should the results indicate MCI or AD, is that the patient can better prepare his or her family for future decisions regarding his or her care. An important disadvantage to undergoing screening that can be explained to the patient is that knowing one has MCI or early AD may significantly and negatively affect quality of life for that

up testing so the psychiatrist can initiate medication as soon as possible if or when the patient shows signs of AD.

An ethical question psychiatrists may consider when they treat patients with MCI is whether they should prescribe these patients a cholinesterase inhibitor.<sup>14</sup> After all, the use of a cholinesterase inhibitor to treat patients with MCI is not evidence based and there are several potential side effects.<sup>5,15</sup> The argument in support of its use, however, grows stronger for patients with greater risks of developing AD, such as those

psychiatrist *can* do for the patient.<sup>19</sup> The rationale of respecting a patient's autonomy more when the treatments offer less underlies analogously the use of a "sliding" (as opposed to a uniform) standard for determining a patient's competency.

## TREATING PATIENTS WITH EARLY AD

When treating a patient with AD, the psychiatrist should always keep in mind that during all stages of this disease, the patient's quality of life is not determined wholly or even mostly by the extent of his or her cognitive decline. Rather, the quality of life of a patient with AD may be more affected by the quality and extent of his or her social relationships, especially during the earlier stages of AD.<sup>20</sup> This does not mean that a patient with AD should force himself or herself to go to every community event or social activity to which he or she is invited, because some events or activities may cause undue stress to the patient.<sup>2</sup> Rather, the psychiatrist should encourage the patient with AD to make choices that will reduce exceptional stress, keeping in mind that the things that cause stress to a patient with AD will constantly change.<sup>21</sup>

Patients with AD and their caregivers and family members should know that while these patients lose cognitive functioning in some areas, other areas of functioning may remain intact.<sup>22</sup> Currently, research is being conducted to determine how patients with AD can use their residual strengths to better compensate for their illness.<sup>23</sup> In other words, a patient with AD may continue to use the areas of functioning as "islands of strength." These islands may enable them to offset and compensate for functions

...the quality of life of a patient with AD may be more affected by the quality and extent of his or her social relationships [than by level of cognitive functioning], especially during the earlier stages of AD.<sup>22</sup>

individual. A discussion of these pros and cons prior to conducting the screening enhances the patient's autonomy and employs the insight underlying motivational interviewing: It meets the patient "where he or she is" and tailors the psychiatrist's clinical intervention to each patient's present level of accepting or denying that he or she possibly has MCI or AD.<sup>10,11</sup>

## TREATING PATIENTS WITH MCI

Once it is determined that a patient has MCI, the psychiatrist should encourage the patient to obtain optimal care for any other medical conditions, such as hypertension, since certain untreated conditions can exacerbate AD. The psychiatrist may also recommend other measures that may possibly be beneficial, such as eating healthy foods, exercising, and engaging in activities that stimulate the brain.<sup>12,13</sup> The psychiatrist should also encourage the patient with MCI to continue to come for regular follow-

who have genes that predispose them to acquiring AD and/or have positive family histories of AD.<sup>1,16,17</sup> The "scientific" judgment to prescribe only evidence-based treatments is one of several ethical judgments that can be made during decision-making processes, such as whether to prescribe a cholinesterase inhibitor. Fully informed patients may believe that a treatment is sufficiently effective for them even though it is not evidence based, especially when their disease is very severe and there are no other treatments. The use of this patient-centered alternative judgment is often referred to as "compassionate use." This non-evidence-based judgement is particularly common in the treatment of medical issues in children.<sup>18</sup>

When a patient has a serious illness for which there is no effective treatment other than possibly the one he or she wants to have, respecting his or her autonomy by providing access to this treatment (though it is not evidence based) is one thing the

they have lost, and caregivers can help them do this.<sup>24</sup> For example, a patient with AD may not be able to remember the date, but he or she may remember where the calendar is in the kitchen. The spouse can help the patient compensate for not being able to remember the date by asking the patient where the calendar is instead. This can also prevent possible resentment by the patient for being repeatedly asked something he or she cannot remember (the date).

Another way a caregiver or spouse of a patient with AD can help the patient use areas of functioning is through every day conversations. For example, I was treating a patient with AD who had been a soccer coach. I asked him about the secrets of his coaching success. He told me in much detail how he'd encouraged his players to practice dribbling throughout the house. He enjoyed talking about soccer and he remembered it well, which helped maintain his self esteem.

Psychiatrists also should encourage patients with AD to continue taking on household responsibilities because this also helps patients maintain their self esteem. Caregivers, likewise, should encourage this, though the responsibilities these patients take on may become less demanding over time. A patient with AD may, for example, do the dishes each night after dinner, but then as time goes by, only dry the dishes. As another example of how these patients can gain self esteem by continuing to have responsibilities, a patient with early AD may find value in helping patients with late-stage AD by reading to them.<sup>25</sup>

A caregiver or spouse may at times face uncertainty when deciding how much responsibility he or she should encourage the

patient with AD to take on. On the humorous side, a patient with AD said he was no longer able to clean up his pet's "mess." The patient later acknowledged that this was a ruse.

As the symptoms of AD worsen, the caregiver or spouse should continue to try finding ways to maximize the patient's capacity to do things for himself or herself. For example, a patient with AD may lose the ability to fasten buttons or snaps or operate zippers on clothing. This patient, therefore, may benefit by converting to elastic waistband-only pants so that he or she can continue to put on and take off his or her own pants.

The psychiatrist should also maximize gains from medication in patients with AD. A core example is the use of cholinesterase inhibitors. It may be that an AD patient cannot take either of two cholinesterase inhibitors because of side effects. What next? Should the psychiatrist consider a third cholinesterase inhibitor? What if the patient cannot tolerate any inhibitors? Perhaps the psychiatrist should then consider prescribing memantine, which has not been proven effective during the mild stage of AD.<sup>26</sup> But the psychiatrist might reasonably consider this intervention if a patient is not able to tolerate cholinesterase inhibitors. Should the consideration of the psychiatrist go beyond this? One study showed that donepezil may be safe and effective at higher than usual dosages.<sup>27</sup> This higher dosage could help some patients and thus increase their quality of life. Yet, this higher dosage may be more problematic, because it may be impossible to know whether this higher dosage is helping. The point is the psychiatrist should not decide prematurely that medications will not help a patient

with AD when this may not be the case.

## **TREATING PATIENTS WITH LATE-STAGE AD**

In the later stages of AD, it is increasingly important that a patient's caregiver and/or spouse know that this patient's quality of life is not determined solely or mostly by his or her cognitive status. Data suggest that many caregivers do not know this.<sup>3,4</sup> If caregivers assume the opposite and give patients with AD less personalized care than they could, this erroneous assumption may do more harm to the patient than good.

One concept that is particularly critical when caring for patients with late-stage AD is assisting these patients' caregivers. One way a psychiatrist can help a caregiver immensely is by finding ways to help alleviate his or her most "catastrophic" fears, which I find usually are the following: 1) having an emergency situation he or she cannot handle and 2) "falling" apart or not being able to cope emotionally with the patient any longer. Accordingly, a psychiatrist can take measures to ensure that a caregiver has a phone number he or she can call for help 24 hours a day. The psychiatrist can also walk through different scenarios with the caregiver telling him or her exactly what to do step by step in the event an emergency situation occurs to help prevent the caregiver from feeling overwhelmed. The psychiatrist might also anticipate times in which a caregiver is likely to feel exceptionally stressed, such as when he or she has to take the patient to a medical appointment that in the past the patient has refused. In this example, the psychiatrist could take the initiative to call the caregiver and ask how things "went." This may help to

reassure the caregiver, especially over time, that there is indeed “someone else” there to help.

Another way a psychiatrist can assist the caregiver is by helping him or her find others who can provide needed knowledge and support. Caregivers who have previously cared for patients with AD can be uniquely helpful to other caregivers. They can make the difference between caregivers (and consequently the patients) not only surviving but to a relative degree thriving. Caregivers can provide emotional support to each other. Many former and current caregivers who have found ways to care for patients with AD successfully want to help other caregivers because they know how agonizing caring for

tell her husband that it was his former company calling to tell him he should bathe. This worked.

### **HELPING PATIENTS WITH END-STAGE AD**

In the last stages of AD, patients with this disease may need to reside in institutions. If this is the case, it is preferable that patients make this transition while they can still recognize their family members. This may help reduce feelings of terror they might otherwise feel due to not recognizing anyone or understanding where they are.

Just as it is with caregivers, it is critical that the staff in an institution be aware that a patient's quality of life is not only related to

illustrate the degree to which such measures can and ideally should be carried out. The staff gave some of these patients a nontraditional “towel bath,” using a no-rinse soap and a warm, moist bath blanket, never leaving the patient uncovered. This caused these patients less discomfort and took less time to complete.<sup>28</sup>

Another example of the importance of staff interacting “socially” with a patient with AD is suggested by a particularly intriguing study. In this study, it was found that staff members were often better able to identify the occurrence of dyspnea in patients who were not able to adequately communicate compared to identifying pain in patients who were not able to adequately communicate. For this reason, staff members would give patients with dyspnea more attention because it was more easily recognized than the patients needed it, and so it is

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a patient with AD can be and want to help others not experience the negative aspects of what they went through. I advise caregivers trying to find other caregivers not to stop trying until they find someone who not only “survived,” but survived with zest. Other caregivers may suggest approaches that greatly benefit not only the caregiver's but the patient's quality of life. For example, the spouse of one patient with AD was having difficulty getting her husband to bathe. After receiving feedback and suggestions from other caregivers, she came up with the following solution: Her husband had worked for the same company his entire adult life. His wife learned that she could go to another room and use her cell phone to call the home phone and then pick up the home phone and

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the degree of cognitive decline.<sup>1,3,4</sup> An example of the benefits of social interaction with patients with AD involves a study on patients' responses to staff who helped them shower. These patients seemed to become less agitated and less aggressive when staff took their time and were more caring during the bathing process, despite the fact that this type of bathing was more time consuming and therefore less efficient.<sup>3,28</sup>

Examples of the kinds of “person-centered” care these clinicians offered these patients

theorized that patients with dyspnea did better because they received more positive attention from the staff than the patients who were experiencing pain.<sup>29,30</sup>

This brings us to the topic of treating pain in patients with AD. If (of course) a patient with AD shows signs of pain, the clinician should do all he or she can to relieve it.<sup>31,32</sup> This may pose an exceptional problem, however, when providing pain relief poses serious adverse risks. Conventionally, clinicians tend to give pain relief more readily to



patients who are competent. This makes sense—it respects the wishes and autonomy of the patient who is competent. Yet, it may be that, ethically, clinicians should provide pain relief more readily to patients who are not competent. Patients who are competent often find meaning in other aspects of their lives, which helps offset the pain they feel. Patients who are not competent may be unable to do this. Thus it may be that clinicians should have a lower threshold for relieving the pain of the patient who is no longer competent. Similarly, when patients with AD are in severe emotional pain, the psychiatrist should at least consider giving these patients antipsychotics, notwithstanding the well known greater risks.

Psychiatrists should try to help the loved ones of patients with AD in every way they can, not only because the loved ones are important as individuals themselves, but also because the loved ones are important to patients with AD. After all, the loved ones of a patient with AD will be the ones who come to visit the patient in the institution and are likely to be more caring toward the patient than anyone else. Psychiatrists should try to imagine all the ways in which they can help the loved ones cope with the illness. The psychiatrist may, for example, help spouses of institutionalized patients anticipate sources of hurt and anger they may feel at some point, such as when patients with AD stop recognizing them. An example is a patient who no longer recognized his wife of more than 50 years and found a girlfriend in the institution where he resided. The wife and I had on many occasions discussed the possibility that he may stop recognizing her at some point, and

this dialogue helped her accept this when it finally happened. Often when she would visit, her husband would have one arm around her, though he was not sure who she was, and one arm around his new girlfriend.

Psychiatrists should also anticipate that spouses of patients with AD are often concerned they will die before the patients do, leaving no one to attend to the financial and personal needs of the patients. Spouses may also feel greatly troubled that other members of the family, such as their adult children, have the same fear. Consequently, psychiatrists should take initiative and ask loved ones directly if they have this fear and encourage them to gradually make plans in case this happens in order to reduce their anxieties.

## CONCLUSION

This article highlights several interventions psychiatrists can take to maximize the quality of life of patients who have AD from the time they first present with memory problems to the last stages of this disease. It is important to be aware that the quality of life of the patient with AD is not solely, or in many cases even mostly determined by cognitive capabilities, but rather is significantly determined by social interactions with others. Psychiatrists should anticipate and attempt to meet the needs of the caregivers and loved ones of patients with AD, particularly during the later stages of the disease, as these people play an important role in the social interactions of patients with AD. With no cure for AD available, quality of life issues for patients with AD should be a primary concern of the clinicians who treat them.

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